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ABSTRACT

As new treatments allow chronically ill children to live longer, the relationship between the child's psychological state and his physical condition becomes paramount. Diabetics (N=42) between the ages of 10 and 21 answered questions about their disease. While most respondents did not feel that diabetes had affected relationships with peers, siblings, parents, or school performance, a significant minority believed that diabetes had important effects in at least one area. The Diabetes Opinion Survey, developed to measure a patient's feelings of stigmatization and to assess the relationship of this perception to other patient attitudes about diabetes, was completed by 150 diabetic children. Responses revealed that children who felt stigmatized by diabetes believed that their disease had affected family life, used their diabetes to manipulate others, and felt that other persons, not they, should manage their diabetes. Data from the Parents' Diabetes Opinion Survey revealed that the mothers of "stigmatized" children also believed that diabetes had stigmatized their children, affected family life, and was used by their children to manipulate others. Results of both surveys suggest that a substantial minority of diabetic children feel stigmatized by this disease. (NRB)

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Peer Relationships Among Chronically Ill Children

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Peer Relationships Among Chronically Ill Children

As many as 7-10% of all children suffer from a serious chronic illness or handicap. In addition to visual and hearing impairments, the most common physical conditions include asthma, epilepsy, cardiac conditions, cerebral palsy, and juvenile diabetes. In fact, almost 50% of pediatric practice is concerned with the chronically disabled youngster (Magrab & Calcagno, 1978). Although the disease process itself is often preeminent, there has been a longstanding interest in the interplay between the youngster's psychological state and his physical condition. This is particularly true for chronic illness which the youngster endures throughout his formative years and into adulthood. In years past, many of these illnesses resulted in relatively rapid death (i.e., within 1 or 2 years of diagnosis), and psychological variables were necessarily given little attention in view of physical realities. However, with the advent of new and improved treatments, many youngsters live for years with their illness, making psychological aspects of this process paramount. Despite the acknowledged importance of psychological components to and as a result of the disease process, little research has actually been conducted in this area. Hopefully, this will be corrected as the growing interest in pediatric psychology takes hold. In any event, the currently available literature has focused primarily on the patient's personality or development and the interaction between the patient's disease and family functioning. There is almost no available literature addressing the effect of chronic illness on peer relationships. This is unfortunate but understandable in view of the very minimal role psychology as a science has had in the understanding of this population.

Those psychologists who have been involved have chosen to study the individual and the family first, while acknowledging the importance of social interactions outside of the home.

Chronic illness and its treatment may potentially negatively impact upon a youngster's peer relationships in four ways: (1) visable effects, (2) physical handicaps, (3) social interference, and (4) changed expectations or plans for the future. In each case the chronic illness serves to set the youngster apart from his peers. The fact that he is "different" is emphasized. It is important to note, however, that the extent and type of such effects is very much dependent upon the disease process and its treatment. For example, a child with cancer may have hair loss or the removal of some part of his body. A youngster with cystic fibrosis may cough and wheeze a lot. Many youngsters with chronic illness are short in stature and tend to mature sexually much later than their peers. Physical handicaps also vary with the disease/treatment process. Youngsters who are blind, deaf, or have had a limb amputated are obviously more physically impaired than youngsters who have a more "hidden" chronic illness such as juvenile diabetes. Probably the most common social effect of all chronic illness is school absences due to sickness and hospitalization. However, the extent of such absences varies with the disease and its severity for the individual child. Some youngsters must face early death, others the risk of additional health risks and/or physical handicaps. For all youngsters, expectations and plans for the future are necessarily affected by the realities of their disease.

What I would like to do today is discuss one chronic illness--juvenile diabetes--and describe to you what we do know about the effect of this disease on peer relationships. I will be describing to you some preliminary work we have done on this topic, but two points need to be emphasized. One, this work is necessarily preliminary because of the lack of an already available research literature to draw upon. Two, while our results may have some bearing on youngsters with other kinds of chronic illnesses, overgeneralization should be avoided. Each illness has its own idiosyncratic aspects and varies in degree of severity and life expectancy. Other illnesses may impact more or less on peer relationships and the nature of this impact may be different.

Juvenile diabetes is the most common endocrine disorder of childhood. It is caused by insufficient insulin production by the pancreas and requires daily insulin injections for survival. Treatment is relatively complex, requiring urine testing 2-4 times a day, frequent meals and other dietary constraints. Treatment is further complicated by insulin needs which vary depending upon diet, exercise, physical health or illness, and the child's emotional state. Diabetes is a "hidden" disease in that there are few visable effects or physical handicaps. The fact that a youngster has diabetes is not apparent to anyone and his activities need not be limited by the disease. The exception is the insulin reaction which in its worst form results in the youngster's becoming comatose. Death may ensue unless sugar is administered. There is some evidence that youngsters fear and are

embarrassed by such reactions. At the same time, youngsters and adults close to the child must know what to do should such a reaction occur. Diabetes itself results in no physical handicaps. However, complications related to diabetes, including retinopathy, renal failure, and neuropathy, can result in limited function. Most of these complications do not occur in children with the disease but must be faced in adulthood after 15-20 years living with the illness. Potential social interference include missed school, limited activities outside of the home such as camp or staying overnight with a friend, and the necessity of eating regularly and avoiding foods (candy, ice cream, cake) that peers may regularly enjoy. Daily urine testing and shots may also serve to make the youngster feel and appear different from others. Although these treatment activities may be hidden up to a point, any continual, close contact with peers will make them apparent. Future plans are necessarily affected because some employers will not hire persons with this disease due to insurance costs or other reasons (e.g., the armed forces will not accept persons with juvenile diabetes). Issues surrounding marriage and children often arise as the disease is hereditary. Pregnancy is a risk for the female diabetic and sexual impotence is a side effect of the disease process in men. The specter of health complications including blindness, renal disease, and heart disease is a never ending reminder of the pervasive effect diabetes can have on the quality and length of an individual's life.

It is interesting to note that a great deal of previous research has assessed the personality characteristics of the diabetic child

(see Johnson, 1980, for a review). While no one personality trait or type has been consistently reported, there is some evidence that a portion of youngsters with this disease feel isolated and alienated from peers. In fact, of all the personality traits assessed, the evidence for peer or social relationship problems is the strongest. However, the nature of these relationship problems is not entirely clear. While clinicians often offer descriptive essays as to what these problems might be, little data had ever been gathered from the patients themselves.

In our first study, we simply asked 42 youngsters with diabetes a series of questions about what it was like for them to live with diabetes. A structured interview format was used with patients ranging from 10-21 years attending an outpatient clinic. The youngsters had had diabetes for 4 months to 16 years with a mean duration of 7.5 years.

Table 1 shows the results of a series of questions addressing family relationships. A third of the youngsters reported that siblings believed they received special treatment because of their diabetes and a quarter believed their activities had been limited. Perhaps more interesting is the high percentage of youngsters who believed their diabetes had increased parental worry, disagreement, and money problems. A much smaller percentage acknowledged increased parental guilt or changed family eating patterns. Over all, a quarter to one-third of the youngsters interviewed believed that they were treated differently by their parents because they had diabetes. Most youngsters believed their diabetes had significantly affected their parents.

Table 2 describes the youngsters' responses to questions about the impact of diabetes on peer relationships. Most (93%) told their friends they had diabetes and most believed the disease had not affected their interactions with friends. Yet, a significant minority of youngsters reported they had been teased or in some way treated differently. The most common reaction peers expressed was surprise or disbelief (e.g., "I don't believe you"; "You're kidding me," or "You're putting me on").

Over half of the youngsters believed their diabetes had affected them at schoo' although answers to this question varied considerably. Over a third believed they had missed a lot of school as a result of diabetes and a fifth did not participate in all school activities. Physical education was the activity most often missed. Some 15% of the youngsters expressed concerns about what they ate during school hours (see Table 3).

Answers to questions regarding future plans are depicted in Table 4. The study's sample seemed to be evenly divided as to whether or not diabetes would affect future jobs or health. In contrast, most youngsters did not believe it would influence who they would marry.

From the results of this first exploratory investigation, we drew two tentative conclusions. First, while most youngsters did not feel diabetes had affected relationships with peers or siblings, school performance, or how their parents treated them, a significant minority of youngsters (20-35%) believed diabetes had had important effects in one or more of these areas. Second, the majority of youngsters

did believe that diabetes had affected their parents and would affect their futures. It seems that while most youngsters with this disease do not deny its impact on one or more aspects of their lives, there may be a subgroup of youngsters who feel particularly stigmatized or alienated.

Our next study was designed to develop a measure of how stigmatized or "different" a patient feels and to assess the relationship of this perception to other attitudes the patient has toward diabetes. We did this by developing an instrument called the Diabetes Opinion Survey. The patient reads a series of statements and agrees or disagrees with each using a 7-point scale. Ten scale scores are calculated including a score for Stigma. Items making up the Stigma Scale of the DOS are presented in Table 5. In a sample of 150 patients, the scale's reliability, using Chronbach's Coefficient Alpha, was $r = .80$.

Table 6 shows the correlations between a child's Stigma Scale score with all other scale scores on the Diabetes Opinion Survey. Note that the strongest relationships are between Stigma and External Control, Family Interruption, and Manipulativeness. What is visually apparent from Table 6 was confirmed when a factor analysis was conducted using this data. Two factors emerged accounting for almost 60% of the variance. The first factor consisted of high loadings on Stigma, External Control, Family Interruption and Manipulativeness. Youngsters who feel different because of their diabetes also believe that diabetes has affected family life. They tend to use the disease to get what they want or to get out

of activities they don't want to do. Finally, they believe other peop'e (i.e., physicians and parents) should manage their diabetes.

Further support for this particular constellation of patient perceptions is found in Table 7. The child's Stigma Scale Score was correlated with his mother's scale scores on a second instrument we developed--the Parents' Diabetes Opinion Survey (PDOS). Although the correlations are low, the pattern of results is consistent. Youngsters who feel stigmatized, tend to have mothers who believe that diabetes has stigmatized the child, disrupted family life, and is used by the youngster to manipulate others. A mother's External Control Scale Score was not significantly related to her child's Stigma Scale Score. This was expected as External Control on the PDOS assesses whether the mother believes others should manage her child's diabetes while External Control on the DOS focuses on whether the child believes that others should manage his disease.

The results of both of these studies suggest that there is a substantial minority of youngsters (20-35% of the population) who feel particularly stigmatized by diabetes. These feelings of being treated differently seem to be related to a more general view of the disease as being highly disruptive to one's life both within and outside of the family. It appears that many of these youngsters attempt to manipulate others with this "difference." Manipulating others may be particularly important to these youngsters as they believe persons other than themselves exercise the primary control over their diabetes and their lives. There is some evidence that parents of these

"stigmatized" youngsters often agree that diabetes has indeed made their child and their lives "different," usually in a negative way.

Since this is a correlational study, we do not yet know whether the child's feeling different is something he learns from his parents who initially treated him differently because of his diabetes. Of course, the child may have felt "different" to begin with and diabetes only served as an easy target for these pre-morbid feelings of isolation. In such cases, the child's behavior may have subsequently forced parents to treat him differently, further supporting the child's view that diabetes is the cause of all his problems. Yet another alternative is that the disease process itself affects youngsters differentially. Some are sick and hospitalized more than others with some real disruptive effects to both family life and normal social development.

We do not know how feelings of being different as the result of a chronic illness like diabetes affects the child's health or compliance with necessary management tasks. It is somewhat easier to speculate on the negative impact of such perceptions on the child's self-esteem and social behavior toward others. We can all agree that our goal is to help youngsters who have a chronic illness to live as normal lives as possible. It is not as easy to agree on when feelings of being different are appropriate, reality-based perceptions and when they have become pathological barriers to a youngster's health and happiness. Similarly, it is not clear how to (or even if we should) intervene with youngsters who feel stigmatized. Answers to these important clinical questions must depend on a thorough understanding of the

disease process on the patient and the development of appropriate measurement procedures to assess the nature, extent, and consequences of a youngster's feeling "different."

References

Magrab, P., & Calcagno, P. Psychological impact of chronic pediatric conditions. In Magrab, P. (Ed.), Psychological Management of Pediatric Problems, Vol. 1. Baltimore: University Park Press, 1973.

Johnson, S. B. Psychosocial factors in juvenile diabetes: A review. Journal of Behavioral Medicine, 3(1), 95-116, 1980.

Table 1

Impact of Diabetes on Family Relationships

Question	Percent Yes	Percent No
1. Siblings think CWD is given special attention?	35	65
2. Parents stop CWD from going places?	27	73
3. Parents worry more?	71	29
4. Parents feel guilty?	19	81
5. Parents disagree about managing CWD?	62	38
6. Increased money problems?	68	32
7. Changed what family eats?	24	76
8. Changed when family eats?	17	83

CWD = Child with Diabetes

Table 2

Impact of Diabetes on Peer Relationships

Question	Percent Yes	Percent No
1. Diabetes affected peer relationships?	18	82
2. Do you tell your friends?	93	7
3. Have peers teased you?	24	76
4. Do friends treat you different?	17	83

5. How did your friends react when they found out you had diabetes?

Didn't change	33%
Surprise / Disbelief / Curious	43%
Understanding / Helpful	5%
Felt sorry / More serious with me	9.5%
Miscellaneous	9.5%

Table 3

Impact of Diabetes on School Performance

Question	Percent Yes	Percent No
1. Missed much school?	38	62
2. Participate in all school activities?	79	21
3. Affected school work / grades?	10	90

4. How has diabetes affected things at school?

No effect	49%
School absences	10%
Watch what I eat in lunchroom	15%
Tire easily	5%
Miscellaneous	21%

Table 4

Impact of Diabetes on Future Plans

Question	Percent		
	Yes	No	Don't know
1. Will diabetes affect your future?	50	36	14
2. Will diabetes affect your job?	52	41	7
3. Will diabetes affect who you will marry?	5	81	14
4. Will diabetes affect your future health?	48	45	7

Table 5

Items from the Stigma Scale of the Diabetes Opinion Survey

Item	Percent		
	Agree	Neutral	Disagree
People really like you better when you are well.	40.4	21.8	37.8
People never invite me anywhere because they think I'm going to get sick.	14.1	8.2	74.6
When people know you have diabetes they treat you different.	37.7	20.1	42.2
When people ask me, "How are you?" they are really asking about my diabetes.	22.1	20.8	57.1
Most people think that kids with diabetes are handicapped.	28.1	19.6	52.3
Kids really make fun of you when they know you take a shot every day and test your urine.	13.3	9.3	77.3
I never sleep over at a friend's house because of my diabetes.	17.2	8.2	74.6
People feel sorry for me when they find out I have diabetes.	33.6	19.1	47.4

Table 6

Scale Intercorrelations:

Child's Stigma Scale Score with all other DOS Scale Scores

	STIGMA
Attitudes Toward Medical Staff	- .12
EXTERNAL CONTROL	.42**
Moralistic Authoritarianism	.33**
Religious Authoritarianism	.22*
FAMILY INTERRUPTION	.57**
MANIPULATIVENESS	.46**
Internal Av[illegible]s	.30**
Minimization of Severity	.23*
Lie	.16

* $p < .01$

** $p < .001$

Table 7

Scale Intercorrelations:

Child's Stigma Scale Score with Mother's PDOS Scale Scores

Mother's PDOS Score	Child's STIGMA Scale Score
STIGMA	.21*
Attitudes Toward Medical Staff	- .02
External Control	.07
Moralistic Authoritarianism	.14
Religious Authoritarianism	- .10
FAMILY INTERRUPTION	.21*
MANIPULATIVENESS	.23*
Detailed Observation	.12
Overprotectiveness	.18
Lie	.12

* $p < .02$